Hospital Use, Associated Costs, and Payer Status for Infants Born with Spina Bifida

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BACKGROUND: Health care use and costs for children with spina bifida (SB) are significantly greater than those of unaffected children. Little is known about hospital use and costs across health insurance payer types. We examined hospitalizations and associated costs by sociodemographic characteristics and payer type during the first year of life among children with SB. We also examined changes in health insurance payer status. **METHODS:** This study was a retrospective, statewide population-based analysis of infants with SB without anencephaly born in Florida during 1998–2007. Infants were identified by the Florida Birth Defects Registry and linked to hospital discharge records. Descriptive statistics on number of hospitalizations, length of stay, and estimated hospital costs per hospitalization and per infant were calculated during the first year of life. Results were stratified by selected sociodemographic variables and health insurance payer type. **RESULTS:** Among 615 infants with SB, mean and median numbers of hospitalizations per infant were 2.4 and 2.0, respectively. Mean and median total days of hospitalization per infant were 25.2 and 14.0 days, respectively. Approximately 18% of infants were hospitalized more than three times. Among infants with multiple hospitalizations, 16.7% had a mix of public and private health insurance payers. Almost 60% of hospitalizations for infants were paid by public payer sources. Mean and median estimated hospital costs per infant were $39,059 and $21,937, respectively. **CONCLUSIONS:** Results suggest a small percentage of infants with SB have multiple hospitalizations with high costs. Further analysis on factors associated with length of stay, hospitalizations, and costs is warranted. *Birth Defects Research (Part A) 00:000–000, 2012.* © 2012 Wiley Periodicals, Inc.

Key words: spina bifida; healthcare use; hospital costs; health insurance; payer type

INTRODUCTION

Spina bifida (SB) is a neural tube defect that results from a failure of the caudal neural tube to fuse early in embryonic development. The severity of impairment is related to the position of the defect along the spinal column and directly affects a child's mobility and ability to maintain bowel and bladder control (Stevenson and Cate, 2005). In addition, the child is at risk for related comorbidities, such as hydrocephalus, seizures, scoliosis, skin ulcerations, and obesity (Simeonsson et al., 2002; Liptak and El Samra, 2010). A child with SB also might face challenges with educational, social, and psychological development (Stevenson and Cate, 2005).

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After the 1998 implementation of mandatory folic acid fortification of the U.S. cereal grain supply, the occurrence of neural tube defects has notably declined (Honein et al., 2001; Williams et al., 2002; Canfield et al., 2005; Williams et al., 2005, Boulet et al., 2008). The most recent annual U.S. prevalence estimate for SB is approximately 1500 infants (Parker et al., 2010). In Florida, about 70 infants with SB were born each year between 1998 and 2007 (Florida Department of Health, 2010).

Several studies have explored the health care economic burden of SB during childhood (Waitzman et al., 1996; Centers for Disease Control and Prevention, 2007; Grosse et al., 2005; Russo and Elixhauser, 2007; Ouyang et al., 2007; Tilford et al., 2009; Cassell et al., 2011) and in comparison to unaffected children (Waitzman et al., 1996; Centers for Disease Control and Prevention, 2007; Russo and Elixhauser, 2007; Ouyang et al., 2007; Cassell et al., 2011). Based on nationally weighted data from the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project (HCUP) 2003 Kids' Inpatient Database (KID), the mean hospital charges per neonatal admission for infants born with SB was $65,342 (Centers for Disease Control and Prevention, 2007). In comparison, the mean hospital charge per neonatal admission for uncomplicated births was much lower, $1844 (Centers for Disease Control and Prevention, 2007).

Two recent studies explored health care expenditures for infants born with SB. Cassell et al. (2011) compared health care expenditures among North Carolina Medicaid-enrolled children with SB with and without hydrocephalus for different age groups, including during the first year of life. The authors reported that infants born with SB who developed hydrocephalus had Medicaid health care expenditures 2.6 times higher than infants born with SB who did not develop hydrocephalus (Cassell et al., 2011). Using national private health claims data, Ouyang et al. (2007) examined medical and prescription expenditures and found that individuals born with SB incurred the highest average total expenditures during their first year of life. Previous research on this topic suggests that the severity and health care costs of this birth defect continue to make it an important public health problem.

Despite these estimates of the health care economic burden associated with SB, gaps remain in our understanding. To our knowledge, no study has examined hospitalizations, length of stay, associated costs by health insurance payer type, and by selected demographic characteristics for infants with birth defects, including SB. Our aim was to describe hospital use, costs, and payer type in the first year of life for children born with SB, using data from a statewide, population-based birth defects registry linked to a statewide hospital discharge database.

METHODS

This study was a retrospective, statewide, population-based analysis of hospital use and costs of infants with SB born in Florida between January 1, 1998, and December 31, 2007. Data for this study were obtained from the Florida Department of Health Vital Statistics, the Florida Birth Defects Registry (FBDR), and the Florida Agency for Health Care Administration (AHCA).

The FBDR is a statewide, population-based surveillance system that uses passive case-finding techniques to identify infants with birth defects during the first year of life (Florida Department of Health, 2010). The FBDR includes live-born infants whose mothers were residents of Florida at the time of the infant's birth. The FBDR excludes infants who were adopted and whose mothers delivered out-of-state (Florida Department of Health, 2010). The Florida Department of Health Vital Statistics provides official birth and death records, which are linked to the FBDR. Infants with SB without anencephaly were identified by the FBDR, using the International Classification of Disease, 9th revision; Clinical Modification (ICD-9-CM) codes 741.00–741.9.

The statewide AHCA oversees Florida's Medicaid program and the licensure of the state's 41,000 health care facilities (Agency for Health Care Administration, 2011). The AHCA data include information on inpatient and outpatient hospital use and charges for all registered Florida hospitals, birth centers, and surgical centers in the state (AHCA, 2011). Hospitalizations initiated during the first year of life, including birth hospitalizations and post-birth hospitalizations, were considered in the analysis. To allow for one year of hospitalizations for each infant with SB, AHCA data from 1998 through 2008 were linked to the FBDR.

Health care utilization variables were obtained from the AHCA data and included the number of hospital admissions, total inpatient charges, length of stay, and principal payer type for each hospitalization and per child. A hospitalization was defined as a single episode of hospital care, whether or not the hospital admission included an accompanying hospital transfer (Colvin and Bower, 2009). If hospital discharge records showed that an infant was admitted to a hospital on the same day the infant was discharged from another hospital, the two admissions were merged into one hospitalization. If a one-day difference existed between a discharge from one hospital and an admission to another hospital and the records included a ''transfer'' code, the two admissions were also merged into one hospitalization.

The health insurance principal payer type was obtained from the AHCA hospital discharge records and was reported by three categories: 1) public, including Medicare, Medicaid, KidCare (Florida's state children's health insurance program), and Veterans benefits; 2) private or employer-based insurance, including military coverage (CHAMPUS/TriCare); and 3) self-pay, no insurance, or under-insured. The self-pay, no insurance, or under-insured category was defined as either no third party coverage or <30% estimated insurance coverage.

Total inpatient charges were adjusted to 2011 dollars using hospital industry data from the Producer Price Index (United States Department of Labor, 2011). Total inpatient charges were also converted to total estimated hospital costs, using the 2009 average all-payer inpatient hospital cost-to-charge ratio for the state of Florida, provided by the AHRQ. The most current average all-payer inpatient hospital cost-to-charge ratio, based on the average of 217 reporting Florida hospitals in 2009, was 0.281 (Agency for Healthcare Research and Quality: Health Care Utilization Project, 2009).

Descriptive statistics on the number of hospitalizations, length of stay, and estimated hospital costs were calcu-

lated for all hospitalizations initiated in the first year of life, but not necessarily completed during infancy. These results were further stratified by birth hospitalization and post-birth hospitalizations. Hospital resource utilization results were stratified by selected demographic variables and by principal health insurance payer type. Changes in principal payer type during the first year of life also were assessed.

For the bivariate analyses, we used chi-square tests to examine crude associations between selected demographic variables and number of hospitalizations, lengths of stay, and estimated total inpatient costs. Average length of stay was divided into four categories: <7 days, 7–14 days, 15–28 days, and >28 days. Number of hospitalizations was divided into three categories: 1, 2–3, and ≥4 hospitalizations. Average total estimated costs were divided into three categories: <$10,000, $10,000–$25,000, and >$25,000.

All analyses were conducted using SAS software, version 9.2 (SAS, Cary, NC). This study received institutional review board approvals from the University of North Carolina at Charlotte, the Florida Department of Health, and the University of South Florida.

RESULTS

The FBDR identified a total of 669 infants with SB without anencephaly. Infants with SB included both isolated (SB ICD-9-CM code only) and multiple defects (SB and another major birth defect). Infants with SB were born live between 1998 and 2007. Of the 669 infants, we were unable to link inpatient hospital discharge data for 54 infants. The final sample size for analysis was 615 infants with SB without anencephaly and included infants who died.

Characteristics of Mothers and of Infants Born with SB

Of 615 infants with SB, 52.5% of mothers were non-Hispanic white, 24.9% were Hispanic, and 21.0% were non-Hispanic black. Mean maternal age was 27.5 years old (data not shown), and 41.6% of mothers had at least some college education. In addition, 51.7% of infants were female, 26.5% were born preterm (<37 weeks gestation), and 19.9% were born low birth weight (<2500 grams). About 7% (n = 41) of infants with SB died in the first year of life. Among these, 13 infants died in the first week of life (2.1% of the entire study sample). Of the 615 infants with SB, 74.8% (n = 460) of infants had an ICD-9-CM code of only SB; that is, there were no additional birth defects ICD-9-CM codes present (Table 1).

Table 1
Selected Maternal and Infant Characteristics for Infants Born with SB in Florida, 1998–2007 (n = 615)

Characteristic	No.	%*
Maternal characteristics		
Age (in years)		
<20	59	9.6
20–24	165	26.8
25–29	165	26.8
30–34	129	21.0
≥35	96	15.6
Race/ethnicity		
Non-Hispanic white	323	52.5
Hispanic	153	24.9
Non-Hispanic black	129	21.0
Marital status		
Married	368	59.8
Not married	247	40.2
Education		
<High school diploma	138	22.4
High school graduate	213	34.6
At least some college	256	41.6
Infant characteristics		
Sex		
Female	318	51.7
Male	297	48.3
Preterm Birth (<37 weeks gestation)		
Yes	163	26.5
No	449	73.0
Low birth weight (<2500 grams)		
Yes	122	19.9
No	492	80.0
Presence of other birth defects		
Isolated (SB only)	460	74.8
Multiple (SB and another birth defect)	155	25.2
Hospitalizations in first year of life		
1 hospitalization	232	37.7
2–3 hospitalizations	275	44.7
≥4 hospitalizations	108	17.6
Deaths in infancy (≤365 days)	41	6.7

SB, spina bifida.

Number of Hospitalizations, Length of Stay, and Total Estimated Hospital Costs per Infant and by Principal Payer Type

Approximately 38% of infants with SB had only one hospitalization during the first year of life (Table 1). Mean and median number of hospitalizations per infant was 2.4 and 2.0, respectively. Mean and median total days of hospitalization per infant were 25.2 and 14.0 days, respectively. Mean and median total estimated hospital costs per infant were $39,059 and $21,937, respectively (Table 2). These types of results were expected because of the infants' complex medical needs at this age.

Among the 615 infants, 49.9% had a public payer source for all hospital admissions, 38.4% had a private payer source for all hospital admissions, and 1.3% were self-pay, underinsured, or had no insurance. The remainder (10.4%) had multiple principal payer sources during infancy. When stratified by birth versus post-birth hospitalizations, 48.8% of infants with birth hospitalizations and 51.0% of infants with post-birth hospitalizations were covered by public payer sources alone. About 39% of infants with a birth hospitalization and 35.2% of infants with post-birth hospitalizations had private insurance as a principal payer without another payer source (Table 3).

Among infants with only public payer sources for first-year hospitalizations, mean and median lengths of stay for the birth hospitalization were 19.5 and 11.5 days, respectively, and 15.4 and 6.0 days for post-birth hospitalizations, respectively. For infants with only private insurance coverage during first-year hospitalizations, mean and median lengths of stay were 14.0 and 8.0 days, respectively, and 10.4 and 4.0 days, respectively, for post-birth hospitalizations. Infants with mixed payer types

Table 2
Number of Hospitalizations, Total Length of Stay, and Total Estimated Hospital Costs* for Hospital Admissions Initiated in First Year of Life per Infant for Infants Born with Spina Bifida in Florida, 1998–2007

	Birth hospitalization[a] (n = 570 infants)			Post-birth hospitalization[b] (n = 406 infants)			All hospitalizations during infancy[c] (n = 615 infants)		
	Mean	Median	Range	Mean	Median	Range	Mean	Median	Range
Number of hospitalizations	1.0	1.0	Not applicable	2.2	2.0	1–11	2.4	2.0	1–12
Length of stay (in days)	17.1	10.0	0–221	14.2	5.0	0–255	25.2	14.0	0–476
Total estimated hospital costs*	$24,818	$15,408	$96–$600,313	$24,323	$9,215	$609–$750,379	$39,059	$21,937	$96–$1,350,690

*Estimated costs in 2011 U.S. dollars. Estimated costs calculated as total charges adjusted to Florida's average hospital cost-to-charge ratio (Agency for Healthcare Research and Quality, Health Care Utilization Project, 2009). Inpatient charges include all hospital facility charges (excludes professional fees): pharmacy, medical and surgical supplies, laboratory, radiology and other imaging, cardiology, operating room, anesthesia, recovery room, emergency room (if an inpatient hospital admission originated in the emergency room), treatment or observation room (if a visit resulted in an inpatient hospital admission) charges (Agency for Health Care Administration, 2011).

[a]Birth hospitalization defined as a first hospitalization with age at admission of 0 days or a first hospitalization with an age at admission of 1 day with an accompanying indication of hospital transfer.

[b]Post-birth hospitalization defined as a first hospitalization with age at admission of >1 day or any hospital admission subsequent to a birth hospitalization during the first year of life.

[c]All hospitalizations defined as birth and/or post-birth hospitalization(s) during the first year of life. The total ''n'' for all hospitalizations is not the sum of birth and post-birth counts because an infant may appear in either one or both hospitalization categories.

over their first-year hospitalizations had mean and median lengths of stay of 18.4 and 10.0 days for their birth hospitalizations and 19.8 and 7.0 days for post-birth hospitalizations, respectively (Table 3).

Among infants with only a public principal payer, estimated mean and median estimated hospital costs for the birth hospitalization were $25,770 and $17,884, respectively. Estimated mean and median costs for post-birth hospitalizations among infants with only public payers were $24,880 and $9108, respectively. Among infants with only private payers, estimated mean and median hospital costs for the birth hospitalization were $22,072 and $12,762, respectively, and mean and median post-birth costs were $18,024 and $8836, respectively. Infants with mixed payer types had estimated mean and median birth hospitalization costs of $31,005 and $19,656, respectively. For post-birth hospitalizations, infants with mixed payer types had estimated mean and median costs of $38,348 and $11,820, respectively (Table 3).

Among infants who had multiple hospital admissions (n = 383), 16.7% (n = 64) had a mix of payer types during the first year of life (e.g., changed from a public to private payer source). Twice as many infants changed from a private to a public payer over the course of their first-year hospital admissions (n = 20) compared with infants that changed from a public to a private payer (n = 9) (data not shown).

Hospitalizations, Length of Stay, and Total Estimated Hospital Costs per Hospitalization by Principal Payer Type

Among all hospitalizations during the first year of life for infants with SB (n = 1456 hospitalizations), 58.3% were covered by public insurance, 39.4% were covered by private or employer-based insurance, and 2.2% of admissions were self-pay, were underinsured, or had no insurance (Table 4).

Mean and median lengths of stay per hospitalization across all principal payer types were 10.7 and 4.0 days, respectively. For hospitalizations covered by self-pay, or were under-insured or had no insurance, mean and median lengths of stay were 13.2 days and 6.0 days, respectively. For hospitalizations covered by public insurance, mean and median lengths of stay were 11.2 and 5.0 days, respectively. In comparison, for hospitalizations covered by private insurance coverage, mean and median lengths of stay were 9.7 days and 4.0 days, respectively (Table 4).

Mean and median total estimated hospital costs per hospitalization across all payer sources were $16,498 and $7002, respectively, adjusted to 2011 dollars (Table 4). When stratified by principal payer type, mean and median total estimated hospital costs for publicly funded hospital admissions were $16,537 and $7218, respectively. Mean and median total estimated hospital costs for privately funded hospital admissions were $16,245 and $6789, respectively (Table 4).

When stratified by principal payer type and by birth versus post-birth hospitalizations per hospitalization, mean and median total estimated hospital costs for publicly funded hospital admissions were $25,424 and $18,212, respectively, for birth hospitalizations and $11,854 and $5376, respectively, for post-birth hospitalizations. Mean length of stay for publicly funded admissions was 19.0 days for birth hospitalization, with a median length of stay of 11.0 days, and 7.1 days for post-birth hospitalizations, with a median length of stay of 3.0 days. For privately funded hospital admissions, mean and median total estimated hospital costs were $24,170 and $12,978, respectively, for birth hospitalizations, and $10,000 and $5585, respectively, for post-birth hospitalizations. In contrast, for privately funded admissions, mean length of stay was 14.9 days for birth hospitalization with a median of 8.0 days, and mean length of stay of 5.5 days for post-birth hospitalizations with a median of 3.0 days (Table 4).

Table 3
Total Estimated Hospital Costs* and Length of Stay per Infant by Principal Payer Type for Hospitalizations Initiated During First Year of Life for Infants Born with Spina Bifida in Florida, 1998–2007 (N = 615)

Principal payer type	Birth hospitalization[a] (N = 570 infants)					Post-birth hospitalizations[b] (N = 406 infants)					All hospitalizations during infancy[c] (N = 615 infants)				
		Total estimated hospital costs		Length of stay (days)			Total estimated hospital costs		Length of stay (days)			Total estimated hospital costs		Length of stay (days)	
	No.	Mean	Median	Mean	Median	No.	Mean	Median	Mean	Median	No.	Mean	Median	Mean	Median
Public[d]	278 (48.8%)	$25,770	$17,884	19.5	11.5	207 (51.0%)	$24,880	$9108	15.4	6.0	307 (49.9%)	$40,111	$23,710	28.0	16.0
Private or Employer-based[e]	221 (38.8%)	$22,072	$12,762	14.0	8.0	143 (35.2%)	$18,024	$8836	10.4	4.0	236 (38.4%)	$31,590	$18,555	19.4	12.0
Self, no, or under-insured[f]	8 (1.4%)	$18,846	$11,336	10.4	6.5	0	0	0	0	0	8 (1.3%)	$18,846	$11,336	10.4	6.5
Mixed payer[g]	63 (11.1%)	$31,005	$19,656	18.4	10.0	56 (13.8%)	$38,348	$11,820	19.8	7.0	64 (10.4%)	$64,075	$31,781	35.5	19.5

*Estimated costs are in 2011 U.S. dollars. Estimated costs calculated as total charges adjusted to Florida's average hospital cost-to-charge ratio (0.281 in 2009) (Agency for Healthcare Research and Quality, Health Care Utilization Project, 2009). Inpatient charges include all hospital facility charges (excludes professional fees): pharmacy, medical and surgical supply, laboratory, radiology and other imaging, cardiology, operating room, anesthesia, recovery room, emergency room (if an inpatient hospital admission originated in the emergency room), treatment or observation room (if a visit resulted in an inpatient hospital admission) charges (Agency for Health Care Administration, 2011).

[a]Birth hospitalization defined as a first hospitalization with age at admission of 0 days or a first hospitalization with an age at admission of 1 day with an accompanying indication of hospital transfer.

[b]Post-birth hospitalization defined as a first hospitalization with age at admission of >1 day or any hospital admission subsequent to a birth hospitalization during the first year of life.

[c]All hospitalization defined as birth and/or post-birth hospitalization(s) during first year of life. The total ''n'' for all hospitalizations is not the sum of birth and post-birth counts because an infant may appear in either one or both hospitalization categories.

[d]Public insurance included Medicare, Medicaid, KidCare, and Veterans benefits.

[e]Private included employer-based insurance, including military coverage (CHAMPUS/TriCare).

[f]Self-insured, no insurance, or under-insured defined as no third party coverage or less than 30% estimated insurance coverage.

[g]Mixed payer status means that an infant had multiple health care payers for hospitalizations in the first year of life.

Table 4
Total Estimated Hospital Costs* and Length of Stay per Hospitalization by Principal Payer Type for Hospitalizations Initiated during First Year of Life for Infants Born with Spina Bifida in Florida, 1998–2007 (N = 1456)

Principal payer type per hospitalization	Birth hospitalizations[a]					Post-birth hospitalizations[b]					All hospitalizations during infancy[c]				
		Total estimated inpatient costs*		Length of stay (days)			Total estimated inpatient costs*		Length of stay (days)			Total estimated inpatient costs*		Length of stay (days)	
	No.	Mean	Median	Mean	Median	No.	Mean	Median	Mean	Median	No.	Mean	Median	Mean	Median
Public[d]	293 (51.4%)	$25,424	$18,212	19.0	11.0	556 (62.8%)	$11,854	$5376	7.1	3.0	849 (58.3%)	$16,537	$7218	11.2	5.0
Private or Employer-based[e]	253 (44.4%)	$24,170	$12,978	14.9	8.0	321 (36.2%)	$10,000	$5585	5.5	3.0	574 (39.4%)	$16,245	$6789	9.7	4.0
Self, no, or under-insured[f]	24 (4.2%)	$24,245	$11,532	16.3	7.5	9 (1.0%)	$8231	$4309	5.2	4.0	33 (2.2%)	$19,877	$9524	13.2	6.0
All payer types	570	$24,818	$15,409	17.1	10.0	886	$11,146	$5475	6.5	3.0	1456	$16,498	$7002	10.7	4.0

*Estimated costs are in 2011 U.S. dollars. Estimated costs calculated as total charges adjusted to Florida's average hospital cost-to-charge ratio (Agency for Healthcare Research and Quality, Health Care Utilization Project, 2009). Inpatient charges include all hospital facility charges (excludes professional fees): pharmacy, medical and surgical supply, laboratory, radiology and other imaging, cardiology, operating room, anesthesia, recovery room, emergency room (if an inpatient hospital admission originated in the emergency room), treatment or observation room (if a visit resulted in an inpatient hospital admission) charges (Agency for Health Care Administration, 2011).

[a]Birth hospitalization defined as a first hospitalization with age at admission of 0 days or a first hospitalization with an age at admission of 1 day with an accompanying indication of hospital transfer.

[b]Post-birth hospitalization defined as a first hospitalization with age at admission of >1 day or any hospital admission subsequent to a birth hospitalization during the first year of life.

[c]All hospitalizations defined as birth and/or post-birth hospitalization(s) during first year of life.

[d]Public insurance included Medicare, Medicaid, KidCare, and Veterans benefits.

[e]Private included employer-based insurance, including military coverage (CHAMPUS/TriCare).

[f]Self-insured, no insurance, or under-insured defined as no insurance or no third party coverage or less than 30% estimated insurance coverage.

Associations Between Maternal and Infant Characteristics and Total Estimated Hospital Costs, Length of Stay, and Number of Hospitalizations

There were statistically significant differences in total estimated hospital costs stratified by maternal age, maternal education level, and maternal marital status (Table 5). Among infants born to mothers under the age of 20, 50.9% had total estimated costs of more than $25,000, and 50.3% of infants born to mothers between the ages of 20 and 24 years had total estimated costs of more than $25,000. In comparison, 42.4% of infants born to mothers between 25 and 29 years had estimated total hospital costs of more than $25,000 and only 36.4% of infants born to mothers between 30 and 34 years had estimated total hospital costs of more than $25,000. Fifty-one percent of infants born to unmarried mothers had total estimated hospital costs of more than $25,000, compared to 39.7% of infants born to married mothers (Table 5).

There were also significant differences between mean length of hospital stay and maternal race/ethnicity, preterm birth, and infants born with low birth weight, as well as between number of hospital admissions and infants born with low birth weight (Table 5). Over 18% of infants whose mothers were non-Hispanic black experienced average length of stay per hospital admission of >28 days compared to 7.4% of infants whose mothers were non-Hispanic white and 5.2% of infants whose mothers were Hispanic (Table 5). No statistically significant differences were observed for number of hospitalizations and maternal race/ethnicity, maternal age and marital status, maternal education, infant sex, and infants born preterm.

DISCUSSION

This study provided state-wide, population-based information on total estimated hospital costs and hospitalizations for hospitalizations initiated, but not necessarily completed during the first year of life, for infants born with SB in Florida. Total mean and median estimated hospital costs per infant were $39,059 and $21,937, respectively. We found the mean length of stay for birth hospitalizations, 17.1 day (across all payer types), was slightly higher than the 15.1 day previously reported using AHRQ HCUP 2003 KID data (Centers for Disease Control and Prevention, 2007). The difference could reflect differences in ascertainment methods of infants with birth defects because the AHRQ HCUP KID (Agency for Healthcare Research and Quality, 2009) analysis did not ascertain infants with birth defects based on birth defects surveillance records.

In this study, children with SB were significantly more likely to have been born with low birth weight or preterm compared to all live-born infants in Florida born during the study period (Florida Department of Health, 2010), which is consistent with previous findings (Petrini et al., 2002; Honein et al., 2009; Purisch et al; 2008). Infants with SB born with low birth weight and preterm may have prolonged hospitalizations and secondary conditions, such as urinary tract infections and respiratory distress syndrome, which can result in higher hospital use and costs. The other selected demographics in our study were similar to the overall demographics of live-born infants and mothers in Florida during the study

Table 5
Distribution of Selected Demographics by Number of Hospitalizations, Average Length of Stay, and Total Estimated Hospital Costs[a] per Infant for Hospitalizations Initiated during the First Year of Life for Infants Born with Spina Bifida in Florida, 1998–2007 (N = 615)

	Number of hospitalizations				Average length of stay					Total estimated inpatient costs[a] per infant			
Characteristic	1	2–3	≥4	*p* value*	<7 days	7–14 days	15–28 days	>28 days	*p* value*	<$10,000	$10–25,000	>$25,000	*p* value*
Maternal characteristics													
Race/Ethnicity													
Non-Hispanic White	115 (35.6%)	148 (45.8%)	60 (18.6%)	0.831	165 (51.1%)	99 (30.7%)	35 (10.8%)	24 (7.4%)	**0.019**	86 (26.6%)	99 (30.7%)	138 (42.7%)	0.136
Hispanic	58 (37.9%)	72 (47.1%)	23 (15.0%)		77 (50.3%)	50 (32.7%)	18 (11.8%)	8 (5.2%)		39 (25.5%)	54 (35.3%)	60 (39.2%)	
Non-Hispanic Black	55 (42.6%)	52 (40.3%)	22 (17.1%)		38 (37.2%)	37 (28.7%)	20 (15.5%)	24 (18.6%)		24 (18.6%)	35 (27.1%)	70 (54.3%)	
Age (in years)													
<20	18 (30.5%)	26 (44.1%)	15 (25.4%)	0.651	24 (40.7%)	20 (33.9%)	7 (18.6%)	8 (13.6%)	0.062	8 (13.6%)	21 (35.6%)	30 (50.9%)	**0.036**
20–24	65 (39.4%)	72 (43.6%)	28 (17.0%)		67 (40.6%)	59 (35.8%)	20 (21.8%)	19 (11.5%)		38 (23.3%)	44 (26.7%)	83 (50.3%)	
25–29	55 (33.3%)	78 (47.3%)	32 (19.4%)		84 (50.9%)	52 (31.5%)	19 (18.8%)	10 (6.1%)		45 (27.3%)	50 (30.3%)	70 (42.4%)	
30–34	55 (42.6%)	56 (43.4%)	18 (14.0%)		68 (52.7%)	34 (26.4%)	18 (15.5%)	9 (7.0%)		35 (27.1%)	47 (36.4%)	47 (36.4%)	
≥35	39 (40.6%)	42 (43.8%)	15 (15.6%)		51 (53.1%)	25 (26.0%)	10 (10.4%)	10 (10.4%)		26 (27.1%)	28 (29.2%)	42 (43.8%)	
Marital status													
Married	137 (37.2%)	175 (47.6%)	56 (15.2%)	0.101	191 (51.9%)	106 (28.8%)	44 (12.0%)	27 (7.3%)	0.060	95 (25.8%)	127 (34.5%)	146 (39.7%)	**0.014**
Not married	95 (38.5%)	100 (40.5%)	52 (21.1%)		104 (42.1%)	84 (34.0%)	30 (12.2%)	29 (11.7%)		58 (23.5%)	63 (25.5%)	126 (51.0%)	
Education													
<High school diploma	46 (33.3%)	62 (44.9%)	30 (21.7%)	0.557	61 (44.2%)	44 (31.9%)	16 (11.6%)	17 (12.3%)	0.469	33 (23.9%)	35 (25.4%)	70 (50.7%)	**0.027**
High school graduate	83 (39.0%)	90 (42.3%)	40 (18.8%)		94 (44.1%)	69 (32.4%)	28 (13.2%)	22 (10.3%)		50 (23.5%)	58 (27.2%)	105 (49.3%)	
At least some college	99 (38.7%)	120 (46.9%)	37 (14.5%)		136 (53.1%)	74 (28.9%)	30 (11.7%)	16 (6.3%)		69 (27.0%)	92 (35.9%)	95 (37.1%)	
Infant characteristics													
Sex													
Female	114 (35.9%)	147 (46.2%)	57 (17.9%)	0.607	138 (43.4%)	108 (34.0%)	41 (12.9%)	31 (9.8%)	0.134	74 (23.3%)	100 (31.5%)	144 (45.3%)	0.633
Male	118 (39.7%)	128 (43.1%)	51 (17.2%)		157 (52.9%)	82 (27.6%)	33 (11.1%)	25 (8.4%)		79 (26.2%)	90 (30.3%)	128 (43.1%)	
Preterm birth (<37 weeks)													
Yes	67 (41.1%)	61 (37.4%)	35 (21.5%)	0.066	68 (41.7%)	47 (28.8%)	25 (15.3%)	23 (14.1%)	**0.014**	34 (20.9%)	45 (27.6%)	84 (51.5%)	0.091
No	162 (36.1%)	214 (47.7%)	73 (16.3%)		226 (50.3%)	142 (31.6%)	49 (10.9%)	32 (7.1%)		117 (26.1%)	145 (32.3%)	187 (41.7%)	
Low birth weight (<2500 grams)													
Yes	51 (46.7%)	43 (35.3%)	22 (18.0%)	**0.044**	47 (38.5%)	35 (28.7%)	16 (13.1%)	24 (19.7%)	**<0.001**	27 (22.1%)	36 (29.5%)	59 (48.6%)	0.551
No	175 (35.6%)	231 (47.0%)	86 (17.5%)		248 (50.4%)	154 (31.3%)	58 (11.8%)	32 (6.5%)		126 (25.6%)	154 (31.3%)	212 (43.1%)	

Note: Values may not add up to 100% because of missing or unknown values.
*The *p* values statistically significant at 0.05 level are in bold.
[a]Estimated costs are in 2011 U.S. dollars. Estimated costs calculated as total charges adjusted to Florida's average hospital cost-to-charge ratio (Agency for Healthcare Research and Quality, Health Care Utilization Project, 2009). Inpatient charges include all hospital facility charges (excludes professional fees): Pharmacy, medical and surgical supply, laboratory, radiology and other imaging, cardiology, operating room, anesthesia, recovery room, emergency room (if an inpatient admission originated in the emergency room), treatment or observation room (if a visit resulted in an inpatient admission) charges (Agency for Health Care Administration, 2011).

period, except we had a slightly lower percentage of Hispanic mothers in our study (about 5% lower). In addition, in our study, 50% of infants with SB had only a principal public payer source for all hospitalizations during infancy. In comparison, about 43% of all births in Florida during the study period were paid by Medicaid, a public payer source (Florida Department of Health, 2010).

Our analysis reported length of stay by payer status. First, mean birth hospitalization length of stay was 21.6% shorter for privately funded hospital admissions (14.9 days) than for publicly funded admissions (19.0 days). Similarly, the length of stay for post-birth hospitalizations averaged 5.5 days for privately funded hospital admissions, 22.5% shorter than the average of 7.1 day for publicly funded hospital admissions. Infants with little or no insurance were intermediate but closer to the public payer group. The difference in mean length of stay between public and private payers could potentially reflect worse health status among children with SB with public coverage and also a tendency for children with greater health care needs to transition from private to public insurance. Comparing Tables 3 and 4, the 32 infants who had birth hospitalizations covered by private insurers but had mixed payers for infancy as a whole had a mean length of stay during the birth hospitalization of 18.4 days, compared to 14.0 days for those who had only private coverage throughout infancy.

When evaluating hospital costs by payer type per infant across all first-year hospitalizations, the percent of infants who had only public payers for all hospitalizations increased between birth and post-birth hospitalizations from 48.8% to 51.0%, whereas hospitalizations covered by private payers decreased between birth and post-birth hospitalizations from 38.8% to 35.2%. Some of this change may have resulted from private insurers reaching maximum coverage limits and may be an indirect indication of the severity of an infant's condition. Infants with mixed payer types over their first year incurred higher costs for both birth and post-birth hospitalizations and had greater length of stay for post-birth hospitalizations than children with a single principal payer source. Total estimated hospital costs for the mixed payer group during infancy as a whole were higher by 103% (mean) or 71% (median) than for the privately insured group and by 60% (mean) or 34% (median) than for the publicly insured group. Of even greater importance, among those with single payers, both mean and median costs were about 28% higher for those with public insurance coverage than for those with private coverage. Further exploration of payer patterns over time and across hospitalizations is warranted.

It is well known that a small minority of patients consume disproportionate amounts of health care resources. That is true for the present study as well, with mean hospital costs and length of stay per infant ($39,059 and 25.2 days, respectively) greater than the medians ($21,937 and 14.0 days, respectively). A future analysis that addresses specific comorbidities, similar to the Cassell et al. (2011) study that examined children with SB with and without hydrocephalus, may provide a more complete picture of the health care costs associated with SB during infancy and throughout childhood.

This study faced several limitations. Infants identified for this study were based on the passive surveillance methodologies for identifying infants with birth defects in the FBDR. Whereas widely used, passive surveillance of birth defects does not actively verify the birth defect diagnosis by review of medical records, hospital charts, or nursery logs. Passive surveillance techniques may lead to under-reporting or miss-reporting of infants with birth defects or specific defect type. In addition, because this analysis used data from the FBDR, it is a state-specific study, which might limit generalizability.

The study of the health care economic burden associated with any medical condition is complex (Folland et al., 2010). Health care charges refer to the fees that a health care provider requests for performance of a particular health care service (Agency for Healthcare Research and Quality, 2009; National Institute of Health, 2010), whereas health care expenditures reflect actual dollars paid for health-related services, regardless of the charge, by an individual or by any public or private payer (Agency for Healthcare Research and Quality, 2009; National Institute of Health, 2010). Health care cost is a general term that reflects the dollar amount a health care provider incurs in the delivery of health services (National Institute of Health, 2010). Hospital charges are facility fees and usually do not include professional fees. Hospital charges are almost always higher than costs or expenditures.

While acknowledging these differences in charges, costs, and expenditures, we tried to mitigate the limitation of reporting charges by converting charges to estimated hospital costs based on Florida's average hospital cost-to-charge ratio using the most recent cost-to-charge ratios from AHRQ HCUP (Agency for Healthcare Research and Quality, 2009).

Hospital cost estimates from this study cannot be directly compared with previous estimates for children with SB for several reasons. First, costs are not equivalent to charges or expenditures. Second, some previous studies used a single payer source, such as private health insurance or Medicaid, which can have different reimbursement rates for services. Third, some previous studies did not adjust costs for inflation and/or used different case ascertainment methods.

It is also important to recognize that total estimated hospital costs only represent one component of health care costs, and, therefore, this study did not capture the full health care costs associated with the care of SB during infancy. To better estimate the total cost of care for infants with SB, information on other cost components, such as outpatient costs and prescription drug costs, would be needed. Inclusion of indirect costs, such as the value of care provided by the family within the home or the value of lost parental work time, would also contribute to a more complete understanding of the financial burden of this condition.

Last, we must acknowledge that the principal payer source variable used in this analysis was the expected principal payer source. It is unknown whether or not this was the actual payer source used. Furthermore, we cannot rule out the possibility that some infants may have had dual payer sources.

The primary strength of this study was use of a large, diverse, statewide, population-based sample based on birth defects surveillance data. We also reported results by per hospital admission and per infant. This was a strength of this study because previous studies only

reported one or the other because of inherent limitations of the data sources used. Additionally, we converted the total hospital charges to estimated costs using the AHRQ HCUP cost-to-charge ratio files, which are based on accounting reports from Centers for Medicare and Medicaid Services (AHRQ HCUP, 2009). Multiplication of the hospital charge by the cost-to-charge ratio results in an estimated hospital cost for those charges (AHRQ HCUP, 2009) and is a useful tool for making comparisons across cost and charge data.

Another strength of this study was the inclusion of both public and private payer sources, which provided new information on hospitalization costs associated with multiple payer sources for a population of infants with SB. In addition, examination of payer status by length of stay, estimated costs, and number of hospitalizations added unique information not previously reported in the literature. Our findings reinforce the need to include information from multiple payer sources for analysis of health care costs for this population. This study also reports that hospitalization costs for infants with SB are considerably greater for those with public or mixed insurance coverage than for those with only private insurance coverage, a finding that warrants further study.

Opportunities for future research include further exploration of the types of payer changes that occur during infancy and childhood (e.g., a switch from public to private vs private to public vs a combination of these payer types). Maternal and infant characteristics associated with changes in payer type and the effects of change in payer type on health care resource utilization and health outcomes will also be important to explore.

This descriptive study provided estimates of health care resource utilization, including hospital use and costs and by payer type, for infants born with SB in Florida during 1998–2007. These findings highlight the importance of considering payer type and comorbidities in future estimates of costs associated with SB. This information may be important to health services researchers as they continue to examine access to care for infants with SB and other birth defects.

In addition, this study demonstrated that hospital discharge data collected by birth defects surveillance programs may be used to analyze differences in costs and payer status by selected sociodemographic information. Health service researchers and other state birth defects surveillance programs may collaborate to conduct similar analyses and determine any patterns and differences in results. A more complete understanding of the patterns of hospital use and costs associated with SB and other birth defects can inform program planning and policy development, which may ultimately contribute to improved health care delivery, quality of care, and improved health outcomes for families, infants, and children born with these conditions.

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REFERENCES

Agency for Health Care Administration (AHCA). 2011. Florida Agency for Health Care Administration. Available at: http://ahca.myflorida.com. Accessed November 20, 2011.

Agency for Healthcare Research and Quality (AHRQ). 2009. MEPS Topics: Health Care Costs and Expenditures. Available at: http://meps.ahrq.gov/mepsweb/data_stats/MEPS_topics.jsp?topicid=5Z-1. Accessed February 20, 2012.

Agency for Healthcare Research and Quality (AHRQ). 2009. Health Care Utilization Project (HCUP). Kids Inpatient Dataset (KID). Cost-to-Charge Ratio Files. Available at: http://www.hcup-us.ahrq.gov/db/state/CCR2009KIDUserGuide.pdf. Accessed July 2, 2012.

Boulet SL, Yang Q, Mai C, et al. 2008. Trends in the postfortification prevalence of spina bifida and anencephaly in the United States. Birth Defects Res A Clin Mol Teratol 82:527–532.

Canfield MA, Collins JS, Botto LD, et al. 2005. Changes in the birth prevalence of selected birth defects after grain fortification with folic acid in the United States: findings from a multi-state population-based study. Birth Defects Res A Clin Mol Teratol 73:679–689.

Cassell CH, Grosse SD, Thorpe PG, et al. 2011. Health care expenditures among children with and those without spina bifida enrolled in Medicaid in North Carolina. Birth Defects Res A Clin Mol Teratol 91:1019–1027.

Centers for Disease Control and Prevention (CDC). 2007. Hospital stays, hospital charges, and in-hospital deaths among infants with selected birth defects--United States, 2003. MMWR Morb Mortal Wkly Rep 56:25–29.

Colvin L, Bower C. 2009. A retrospective population-based study of childhood hospital admissions with record linkage to a birth defects registry. BMC Pediatr 9:32.

Florida Department of Health (FDOH). 2010. Report on birth defects in Florida 1998–2007. Tallahassee: Florida Department of Health, Florida Birth Defects Registry. Available at: http://www.fbdr.org/pdf/FBDR_report_May2011.pdf. Accessed February 21, 2012.

Folland S, Goodman AC, Stano M. 2010. The economics of health and health care. 6th ed. Boston: Prentice Hall.xxii,601.

Grosse SD, Waitzman NJ, Romano PS, Mulinare J. 2005. Reevaluating the benefits of folic acid fortification in the United States: economic analysis, regulation, and public health. Am J Public Health 95: 1917–1922.

Honein MA, Kirby RS, Meyer RE, et al. 2009. The association between major birth defects and preterm birth. Matern Child Health J 13:164–175.

Honein MA, Paulozzi LJ, Mathews TJ, et al. 2001. Impact of folic acid fortification of the US food supply on the occurrence of neural tube defects. JAMA 285:2981–2986.

Liptak GS, El Samra A. 2010. Optimizing health care for children with spina bifida. Dev Disabil Res Rev 16:66–75.

National Institute of Health (NIH). 2010. Health economics information resources. U.S. National Library of Medicine: National Institutes of Health. Available at: http://www.nlm.nih.gov/nichsr/edu/healthecon/glossary.html. Accessed February 20, 2012.

Ouyang LJ, Grosse SD, Armour BS, Waitzman NJ. 2007. Health care expenditures of children and adults with spina bifida in a privately insured U.S. population. Birth Defects Res A Clin Mol Teratol 79:552–558.

Parker SE, Mai CT, Canfield MA, et al. 2010. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. Birth Defects Res A Clin Mol Teratol 88:1008–1016.

Petrini J, Damus K, Russell R, et al. 2002. Contribution of birth defects to infant mortality in the United States. Teratology 66 Suppl 1:S3–S6.

Purisch SE, DeFranco EA, Muglia LJ, et al. 2008. Preterm birth in pregnancies complicated by major congenital malformations: a population-based study. Am J Obstet Gynecol 199:287.e1–287.e8.

Russo CA, Elixhauser A. 2007. Hospitalizations for birth defects, 2004: statistical brief #24. Healthcare Cost and Utilization Project (HCUP) Statistical Briefs [Internet]. Rockville, MD: Agency for Health Care Policy and Research (US) 2006–2007.

Simeonsson RJ, McMillen JS, Huntington GS. 2002. Secondary conditions in children with disabilities: spina bifida as a case example. Ment Retard Dev Disabil Res Rev 8:198–205.

Stevenson J, Cate IM. 2005. Assessment of health-related quality of life. In: Wyszynski DF, editor. Neural tube defects: from origin to treatment. New York: Oxford University Press. pp. 361–370.

Tilford JM, Grosse SD, Goodman AC, Li K. 2009. Labor market productivity costs for caregivers of children with spina bifida: a population-based analysis. Med Decis Making 29:23–32.

United States Department of Labor: Division of Consumer Prices and Price Indexes. 2011. Available at: http://www.bls.gov/cpi/. Accessed December 1, 2011.

Waitzman N, Scheffler RM, Romano PS. 1996. The cost of birth defects: estimates of the value of prevention. Lanham: University Press of America, Inc. xiv, 262.

Williams LJ, Mai CT, Edmunds LD, et al. 2002. Prevalence of spina bifida and anencephaly during the transition to mandatory folic acid fortification in the United States. Teratology 66:33–39.

Williams LJ, Rasmussen SA, Flores A, et al. 2005. Decline in the prevalence of spina bifida and anencephaly by race/ethnicity: 1995–2002. Pediatrics 116:580–586.